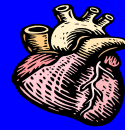
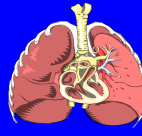
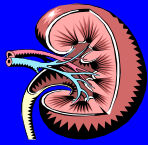
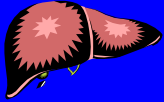


VA National Transplant Program Newsletter



A Publication of VACO Medical /Surgical Services

May 2005/Volume 5

VA National Transplant Program Staff:

- Madhulika Agarwal M.D., M.P.H.: Chief Patient Care Services Officer
- Marianne Mathewson-Chapman, Ph.D., ARNP: Clinical Transplant Manager
- Brenda Salvas: Manager, Liver, Kidney, and Kidney-Pancreas Transplant Program
- Vacancy: Manager, Heart, Lung, and Bone Marrow Transplant Program – Currently Recruiting
- Vacancy: Program Assistant, Transplant Program – Currently Recruiting

Beverly Zinicola Retires

Submitted By: Brenda Salvas
Manager, VA National Transplant Program
VA Central Office, Washington, DC

No fanfare or big farewell party that is the way Beverly wanted to leave. Truly, I believe she just did not want to say goodbye to the outstanding teams at our VA Transplant Centers, our excellent physician review board members, and the wonderful veterans and staff she has worked with from the referring VA medical centers and Central Office this past ten years. Beverly has been a tremendous asset to the VA National Transplant Program, the last of the original staff when the program was centralized here to Washington, DC, in 1995. She has seen and heard so much during her time in transplant, and was the driving force behind the processes currently in place. She and I have worked together for almost seven years, and I could never ask for a better mentor. I will especially miss her scrappy attitude, being the “bad” cop in the office (as she called herself), the budget “bulldog”, and devil’s advocate. Always looking at the big picture and working many extra hours to assure that the veterans, transplant centers and referring medical centers received the assistance they needed in order to resolve any issues in a timely manner.

Change is never easy, and although Beverly has been toying with the idea of retirement for a while she was not ready to step into that part of her life. This was a difficult decision, moving back home to New York to care for her parents, but she knew it was the right choice, and that we do not always get to leave at “our” time.

Beverly, we will miss you, and this is a great loss to the veterans we serve, the Department, and the many co-workers who consider you their friend. Your friends want to wish you well, and we hope you enjoy this next step in your journey. On a personal note, I want to thank you for your kindness to my family and me. You will always have a special place in our hearts! You have made a tremendous difference in many lives through your work in the transplant program, and I have a deep respect for your hard work, dedication, and personal work ethics. I just hope that we can continue to keep the program running as well as you have these past ten years!

After your 22 years with the Department of Veterans Affairs -10 years here in the VA National Transplant Program and 12 years at the Brooklyn VA Medical Center - we wish you good health and God speed. Please keep in touch Beverly, and take care of yourself!

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VHA Seamless Transition Program

Submitted By: Brenda Salvas
Manager, VA National Transplant Program
VA Central Office, Washington, DC

Effective April 27th, Marianne Mathewson-Chapman, Clinical Transplant Manager, was detailed to the VHA Seamless Transition Program. Marianne has been very involved for with ongoing projects regarding the service members returning from active duty. She has briefed many of our servicemen and servicewomen regarding their VA benefits, and the shift of their medical care from the Department of Defense to the Department of Veterans Affairs. The Transition team is working diligently to assure a smooth transition, and Marianne has worked especially hard with the National Guard units returning home now. Keep up the great work Marianne! We know our “future” veterans are in capable hands.

Social Work Corner

We are please to see this section of the Newsletter return, because the VA Social Workers at both the referring VA medical centers and at our VA Transplant Centers play a critical role in the overall transplant process. Thank you to the Nashville Transplant Center Social Workers for their articles this quarter.

*** Ten-Year Milestone Achieved ***

Submitted By: Katrina Stokes, LCSW
Bone Marrow and Kidney Transplant Social Worker
VA Tennessee Valley Healthcare System, Nashville, TN

This month, I will have been working with bone marrow/stem cell transplant patients and their families for eleven years as their social worker. As a professional, you take care of concrete tasks to lighten their load and you do a lot of listening. We have the privilege of trying to help them deal with the uncertainties of living with cancer and the challenges of living the roller coaster ride of diagnosis, treatment, remission, relapse, and end of life issues. There are those times when we watch these brave individuals lose their fight with cancer. We have to wonder is it all worth it? Does bone marrow or stem cell transplant really save lives?

In April, we celebrated a life saved through bone marrow transplant. For the first time here at the Nashville VA Transplant Center, we had a patient here for his 10 year follow-up appointment, a real milestone in the life of someone fighting cancer. Mr. A.J. Duke volunteers regularly at his local VA Medical Center in Clarksburg, WV, and plays an active role in restoring the historical town of Helvetia, WV. Mr. Duke lives his life looking for ways to make a difference in the world around him. He is humbled by and thankful for the gift of life he received through bone marrow transplant. Without having to face our own mortality, our patients show us through their courage and the importance of living each day with joy. In this way, they have given each of us the “gift of life”.



Pictured: Stacey Goodman, M.D.; A.J. Duke, patient; Katrina Stokes, LCSW; Pamela Walden, RN; Stephen Brandt, M.D.; and Nelda Rouse, RN

National Donate Life Month

*** April In Nashville ***

Submitted By: Patricia M. Coffey, LCSW
Heart and Liver Transplant Social Worker
VA Tennessee Valley Healthcare System, Nashville, TN

April is a very exciting time in Nashville. National Donate Life Month is a time to educate our veterans, their families and the general public about organ and tissue donation and transplantation. We are very proud here in Nashville to be the only VA in the country to offer four different types of transplants: kidney, bone marrow, heart and liver (the heart and liver surgeries are done under contract with Vanderbilt University).

On April 5, 2005, a display was set up in the lobby of our VA Medical Center with pictures, brochures, books, lapel pins, green bracelets, bumper stickers, and others items encouraging organ donation. Transplant patients, their families, friends and VA personnel staffed the table throughout the week. Our patients wore name tags indicating their status as either listed, or the date and type of their transplant. Many stimulating conversations occurred because of this identification. Tennessee Donor Services was kind enough to provide t-shirts for our volunteers to wear. One veteran who volunteered said, "I really enjoyed working the table. There is still the need to get the word out because there are many misconceptions regarding organ donation." He promised to help again next year. Katrina Stokes, LCSW, VA Bone Marrow and Kidney Transplant Social Worker, and I had the opportunity to attend a candlelight ceremony honoring donor families on April 22nd at the Tennessee Donor Services. I lit a candle in remembrance of all transplanted veterans who received a second chance at life. The ceremony was a moving tribute that emotionally touched all who attended. Pam Hale, RN, Liver Transplant Coordinator, and I also staffed the Tennessee Donor Service Booth during the Southern Women's Show, March 31st – April 3rd. This three-day event is attended by approximately 100,000 women and highlights their issues and interests. Pam and Michele Hall, Program Support Assistant, Liver Transplant Program, attended the "Give the Gift of Life" Program given by the Vanderbilt University Medical Center and the Tennessee Donor Services on April 26th where a donor family and transplant recipient told their moving stories.

As an ongoing effort in the State of Tennessee, The County Clerk's Association initiated a \$1 voluntary contribution for organ donation education. This year there is a statewide initiative to adopt an Organ Donation license plate. As you see the State of Tennessee, Tennessee Donor Services and our VA have continued to promote donor and tissue awareness. Our work in transplantation has made a difference!

*** Threads of Life Quilt ***

Submitted By: Roberta Ruimy
Administrative Coordinator, Liver and Kidney Transplant Program
VA Medical Center, Portland, OR

The Portland VA Medical Center and the Oregon Donor Program (ODP) celebrated Donor Awareness Month by co-hosting the unveiling of the 7th panel of the Threads of Life Quilt. The quilt was lovingly created by supporters of organ and tissue donation, transplant recipients, and donor family members. Each panel is made of squares individually designed and stitched, with one panel assembled each year. This is the second time the Portland VA Medical Center has been asked to host this inspirational statewide event. The unveiling was held on the evening of April 20th, to coincide with the opening of the Transplant Conference. In attendance were 125 donor families, transplant recipients, healthcare professionals and others who support the mission of the ODP to educate the public about the need for donation. Speakers included our own CEO Jim Tuchs Schmidt, MD; Urban Miyares, a recent kidney transplant recipient attending with his seeing eye dog, Duchess; and Ed Hearn, a former World Series baseball champion who has had three kidney transplants and was also the keynote speaker at the Conference.

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The Portland VA Medical Center has established a close relationship with ODP, encouraging our patients to contribute squares to the quilt, participating in the "Discover OHSU" program to educate teens about organ and tissue donation, and supporting fundraising activities through promotion of the ODP mission. For more information about ways that your medical center might collaborate with organ and tissue donation agencies in your area, feel free to contact any of the VA Transplant Programs. If you would like to view the quilt panels in the Oregon area, visit www.ordonorprogram.org.



Pictured: Urban Miyares, veteran and kidney transplant recipient; Ed Hearn, World Series Champion and 3-time kidney recipient; Jim Tuschmidt, MD, CEO, Portland VAMC; and, Mary Jane Hunt, Executive Director, Oregon Donor Program



Urban Miyares with Duchess and Ed Hearn unveiling the 7th panel of the "Threads of Life" Quilt. Urban's square is part of this panel.

The Threads of Life Quilt is dedicated to the memory of those who gave the "gift of life" and also honors the lives of transplant recipients. Every year, quilt panels are displayed at hundreds of locations across the country to raise public awareness regarding the critical need for organ donors. If your VA would like to display the quilt or learn more about distributing information on a local level, visit www.shareyourlife.org. Local chapters are there to assist you with an event at your facility during upcoming health fairs, blood drives, etc. We would like to encourage our veteran transplant recipients and/or living donors to submit a quilt square for future panels. Quilt squares can be submitted throughout the year, and the local organ donor program can provide further guidance to the VA staff, veteran recipient, or donor.

***** Alive and Grateful! *****

Submitted By: Linda Cook, RN
Clinical Bone Marrow Coordinator
VA Puget Sound Health Care System, Seattle, WA

That was the theme for a recent gathering of marrow and peripheral blood stem cell transplant survivors, families, friends and staff members of the VA-Puget Sound Health Care System Marrow Transplant Program in Seattle, WA. The event was the brainchild of a young man transplanted for leukemia nearly 18 years ago. He was at a point in his life where he began to look back at how far he had come since transplant and became aware of how grateful he was for the gift of life he received and how precious that life was. He initially contacted the transplant program in Seattle with his plan and asked for help in making it happen. It took some creative thinking to navigate the constraints of HIPPA and the lack of funding, but we were able to accomplish it. Many former patients, families and staff members contributed money to help him with expenses and one of our local patients assisted by securing a location for the event.

Invitations were sent to every survivor who had been transplanted in our program and every staff member (past and present). Needless to say, there were some who had been lost to follow up over the years, but

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altogether there were over 300 invitations sent out. The first Nurse Manager, the current Nurse Manager, and the Chief Pharmacist, who have been with the program since it opened in 1982 were all in attendance, along with other staff members who have been with the program for anywhere from one to twenty-two years.

Seventeen survivors and their families from seven different states attended at their own expense. At the reception they were able to express their appreciation and share their stories of recovery. Every survivor had something to say about their experience and how it shaped their life. Some of those present expressed some anxiety about attending the event, but afterwards talked about how affirming and uplifting the experience had been for them. It was as though this was one more step on their path to reclaim their lives. Several survivors who were unable to attend responded by e-mail or letter to express their appreciation and their regrets over not being present. It was fun to hear what was going on in their lives and the lives of their families. One sent a video of himself and his family with remembrances of his time in Seattle and an update on his life as it is today.

As guests arrived, they were asked to sign a poster commemorating the event and then had their picture taken with the poster. Each person was given a nametag to help refresh memories and one of the survivors brought flowers for everyone to wear. We had posters displaying pictures of former and present staff members and a video of those pictures was played during dinner. We were honored to have our Chief Medical Officer, Dr. Gordon Starkebaum and our Transplant Program Director, Dr. Thomas Chauncey attend the program. Both spoke about the transplant program, and were able to hear first hand what the program means to the people it serves.

This was a heart-warming event that gave us an opportunity to reflect upon the work we do and be reminded of the many lives we touch daily. It gave us an opportunity to present our program to the local media in a positive manner and to increase awareness of the importance of continued support for all VA programs. Many of the survivors who were able to attend expressed a desire to repeat this event and talked about how we could encourage greater participation in the future. Over the next few months we will try to gauge the extent of interest and explore ways to continue within the constraints of federal fiscal guidelines.



Pictured: Dr. Gordon Starkebaum with Dr. Thomas Chauncey; patient who hosted event at podium; honored guests.

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*** Raising Awareness In Kansas City ***

Submitted By: Carol Pope RN, BSN, Organ Requestor
VA Medical Center, Kansas City, MO

In an effort to raise employee awareness, veteran participation, and community support, the Kansas City VA Medical Center staff arranged three organ donation projects during April **Organ and Donor Awareness Month**. Under the direction of Carol Pope, RN, Organ Requestor, and with the assistance of two members

of the local Organ Procurement Organization, Carol and company went from nursing unit to nursing unit to drop in on RN's who had 10 to 15 minutes for a mini in-service regarding their new local organ and tissue procurement policy. Members of the OPO team provided a "goodie bag" of various trinkets and candies for those who lent an ear.

On April 12th and May 11th a nursing skills fair was held for all of the patient care nursing staff. More than 200 RN's, LPN's, and PCT's had a chance to sit down and read a condensed animated version of the policy and test their skills on that policy as well as many others. On April 26th, Carol and her volunteer nurse Mary (who agreed to help spread the word) manned an all day booth for staff, visitors, and veterans to stop by and pick up information about why it is important to **DONATE LIFE**, or at least look at the need, discuss it with family, and make an informed decision. Carol is working on a brown bag luncheon with physicians, nurses, social workers, chaplains, and others at the VAMC interested. It is tentatively planned for this fall. "Next year I plan to get the whole hospital involved."

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***** Transplantation At The Loma Linda VA *****

Submitted By: Cyndi Gomez

VA Loma Linda Health Care System, Loma Linda, California



Turn the clock back to the year 1988. A young veteran in his early twenties, who was previously diagnosed with autoimmune hepatitis, now has the signs and symptoms of cirrhosis and liver failure. He had proven to be a genuinely likeable person, and we were all very sad that he would probably not survive more than one year. He had tried his best to complete his education while working as a paramedic, but finally due to liver failure, he arrived at the point that he was barely able to make it through the day. What about liver transplantation? There was no organized transplant program within the VA in those pioneering days when liver transplant centers were just becoming established. Then, I discovered by word of mouth that all hope for our patient was not lost. There was a fledgling program sponsored by the VA and the University of Pittsburgh. After many phone calls and a lot of persistence, we were able to gather a few required tests, a medical history and our patient was off to Pittsburgh for evaluation. Much to our relief and joy, he was deemed an ideal candidate and was soon the recipient of a new liver. Now, 17 years later he has married, raised a family, and has worked fulltime as a computer consultant. He has also been an active participant in the annual transplant Olympics.

This is how I, Cyndi Gomez, first became involved in the VA liver transplant program, and it is amazing to me to look back at how far the program has evolved over the years and its exciting future. Since that time we have had 18 patients from our medical center receive liver transplants, and have acquired 16 more patients from other programs outside of the VA system. Over the years, as the numbers of transplant recipients has increased, it became clear to me that we needed to have a more organized approach to managing these patients. They require special expert care. Having their care fragmented among the staff physicians and gastroenterology fellows did not prove to be efficient. Their clinical course could be complicated and decisions often had to be urgently made. So over the years, with the help of physicians, social workers, and support staff, The Gastroenterology Section at the Loma Linda VA was able to establish the following:

- ❖ A designated liver transplant clinic where all transplanted patients are followed by the same physician;
- ❖ A dedicated chronic liver diseases clinic to manage those patients who are potential candidates;
- ❖ In-house templates to ensure proper completion of all referral packets;
- ❖ Established contacts with social work services and mental health to designate a point of contact for our referrals in order to standardize the information submitted; and,
- ❖ A great transfer coordinator who ensures that all packets are handled in a timely manner, and that patient's get transferred when needed.

(Continued Page 7)

When it became apparent that in spite of our efforts, the patients and their relatives were still not fully informed as to the nature of liver disease and treatment, I organized our hospital's first ever disease related support group. Now in place for over eight years, the first Monday of each month the group is treated to a talk on a liver or health related topic and an open discussion forum. Spouses and relatives are welcome and sometimes attend even when the patient is too ill to participate. Refreshments are served. The mix of pre and post transplant patients and those with chronic liver diseases provides a wealth of information to share. Over the last three years the group has become autonomous, has elected its own officers, and has initiated its own agenda and public outreach programs. This support group has become so popular that we have patients from hospitals in the private sector attend because they were not getting sufficient information from their doctors. Support group members visit and encourage members of the group that are hospitalized. Some members regularly attend other liver support groups and bring new information back to our group.

For the last 3 years the support group has been involved in ORGAN DONOR MONTH. This year's program was a great success. On April 27, 2005, support group members sponsored an information kiosk in front of the hospital canteen. Over 350 brochures were passed out and employees, veterans, and visitors asked many questions. Many of those who made inquiries had not previously given serious thought about becoming an organ donor. Several signed up on the spot. It was emphasized that until a family member or close friend has the need for an organ donation, most give little thought to volunteering. We received help from One Alliance and the San Bernardino County Medical Association as to brochures and supplies. There were several door prizes awarded.



Pictured: Richard Menzel, President, Loma Linda VA Liver Support Group, Nancy Bachman, Ralph Snyder, Larry George, Vincent Lopez, Sherri Stockton, and Gregory Schultz.

Recently, I have been asked to participate in the Central Office transplant work group that has been tasked with automating the transplant referral process. So, over the years, I have been witness to and a participant in the tremendous growth and organization of the VA transplant program. Gone are the days of tracking down that nebulous transplant process somewhere in Pittsburgh. The process is now streamlined with a well-defined algorithm, and it is still improving.

I cannot say enough about the outstanding support for the liver transplant patients that I have received over the years from the team at Central Office led by Brenda Salvas and Beverly Zincola, and the wonderful people at the transplant center at Portland including Roberta Ruimy, Sue Gann, Kelly Konikow, Tom Swanson, Ann Busch, Gordon Wells and Dr. Ham, Dr. Orloff and Dr. Rosen. They have not only helped us with the patients directly, but the educational programs that they have sponsored have been extremely useful in the daily management of our patients. It is a relief to know that you have many people who are genuinely dedicated to the care of our veteran patients. I consider them as part as my family. I look forward to continuing my work in this exciting field of medicine and am truly grateful for having been allowed to contribute in some small way to the care of our veterans.

Conference News

*** Advances in Liver and Kidney Transplantation ***

Submitted By: Roberta Ruimy

Administrative Coordinator, Liver and Kidney Transplant Program, Portland, OR



The Portland VA Medical Center and its affiliate, the Oregon Health and Science University, co-sponsored a successful CME/CEU approved conference in April. The conference was designed to provide a comprehensive overview of the liver and kidney transplantation processes to health care professionals caring for patients with end-stage liver and renal disease by helping them assess potential transplant candidates, facilitate transplant referrals, educate patients, and provide post-transplant follow-up care.

Faculty included transplant specialists in all related disciplines including surgery, medicine, pharmacy, nutrition, psychiatry, and social work from the Portland VA, OHSU, and other VA centers across the country. The conference drew 225 registrants and faculty from 22 states and 33 VA medical centers.

Keynote speaker Ed Hearn, World Series Champion with the New York Mets and author of "Conquering Life's Curves" spoke eloquently and with great humor about his experiences and perspectives as a three-time kidney recipient. Be sure to ask anyone who attended about his unforgettable entrance in a hospital gown! If you were unable to attend the program, please check out our website to view the presentations -- <http://www.va.gov/portland/transplant/Conference/Index.htm>. Enjoy the following photos taken at the program.



Pictured: Sue Gann and Kelly Konikow; Dr. John Ham; several pictures of attendees. Kudos to the Portland team!



Farewell Dr. Butler and Tracy

By the time this issue of the Newsletter is released, both Dr. Javed Butler, VA Heart Transplant Program Director, and Tracy Johnson, NP, Clinical Coordinator, at the Nashville VA Heart Transplant Center, will have left the VA. We would like to take this opportunity to wish both Dr. Butler and Tracy the very best in their future endeavors and take this opportunity to thank them for the wonder care they have provided to those heart transplant patients assigned to the Nashville program. We will miss you both and wish you the very best!

Transplant Referral Packet Helpful Hints

- ❖ Before submitting your packet to VACO, place the documentation in the order of the VACO checklist. This helps to expedite the review so the packet can be expedited to the physician review board.
- ❖ A VA staff physician is responsible for the submission of the transplant referral packet to VACO. The physician should review the social work and mental health evaluations carefully before submission to ensure there is no conflicting info.

VA National Transplant Conference Calls CY 2005

January 12

April 13

July 13

October 13

2:00 pm (Eastern Time)

E-mail agenda items/topics to Brenda Salvas. Dial-in information and agenda are sent to the transplant e-mail groups approximately two weeks prior to the scheduled call.

Websites

<http://www.va.gov/transplant>

<http://vaww.va.gov/transplant>

- ❖ VACO and VA Transplant Center Contact Info
- ❖ Guidelines in Preparing Transplant Referral Packets
- ❖ Templates

<http://www.unos.org>

- ❖ National Transplant Statistics and Information

<http://www.marow.org>

- ❖ National Marrow Donor Program

<http://www.shareyourlife.org>

- ❖ Details On Becoming An Organ Donor

Thank you to all who submitted articles this quarter for the Newsletter. We welcome articles related to solid organ/bone marrow transplant and organ donation. Please e-mail your news to: brenda.salvas@hq.med.va.gov.

The Transplant Newsletter is published quarterly:

February, May, August, and November

Items for the next newsletter are due by **July 31st.**

